

Report to the EOA congress in Krakow 2014



Organization: Deutsche ILCO e.V. (German Ostomy and Colorectal Cancer Association)

Number of members (2014/01/01): **8.007**

- **people with all types of ostomies (because of different diseases or other reasons) and people with colorectal cancer with or without an ostomy:** in total 6.655 members
- **relatives:** 473
- **supporting members:** 879

National Board: max. 8 persons (ostomates or people with colorectal cancer), all volunteers
Employees (only in the national office): 3 full time, 5 part time

Estimated number of ostomates in Germany: more than 100.000 with a final ostomy (maybe about 150.000). Unfortunately there exist no validated data.

Financing of the Deutsche ILCO: membership fee, German Cancer Organisation "Deutsche Krebshilfe", Public Health Insurances and – from time to time – (mostly smaller) donations

Appliance-situation: Good, a lot of different products of different companies are available. Problems: (1) poor independent consultation possible, consultations are mainly given by those who are sellers or distributors of appliances, (2) The further education and the profession of an "enterostomatherapist" is not official acknowledged – everybody is allowed to name himself ET. Most of the ostomates don't know which kind of knowledge "their" ET has.

Type of reimbursement:

Doctors prescribe the products. The appliances are paid by the Health Insurances except 10% → ostomates have to pay these 10% by themselves but at the most 10 EUR per month (120 EUR per year).

If you need more than a - by the health insurances – defined quantity of appliances per month (average consumption) the necessity must be checked and justified by a doctor (and/or a stoma nurse). Otherwise the ostomate has to pay the quantity over the average consumption by himself. Health insurances are allowed to check if the explanations of stoma nurses and doctors are correct.

Activities of Deutsche ILCO:

- 300 local chapters organized in 87 regions
- 8 associations on land level (coordination of visiting service, information, exchange of experiences, organisation of chapters and of regional events)
- about 700 volunteers in all kinds of tasks

National level:

- National Delegates Meetings every 3 years (next July 2014) -> responsible for the election of the national board, for changes of the association's constitutions, for decisions touching the general direction of the association
- Issue of own brochures (*see below*), leaflets and other information, Website
- Journal "ILCO PRAXIS" published 4 times a year
- Seminars/trainings/meetings for the volunteers in different tasks (f.e. chapter leaders, visiting service in hospitals and rehabilitation centres, treasurers, board members)
- Public information meetings
- National conferences (public) like National Urostomy Conference, "ILCO-Tage" (both three-annual) , ILCO ± 35 (annual meeting for younger people)
- Advocacy work in different bodies of experts (f.e. social and health politics, health care system, treatment guidelines and patient guidelines, National Cancer Plan) – depending on the topic the work is done in cooperation with other national selfhelp association.
- Cooperation with Colorectal Cancer Centers
- Cooperation with other selfhelp associations – f.e. DCCV (Inflammatory Bowel Disease Association) and different cancer associations: Joint actions or joint advocacy work.

Special features and successes in the last three years:

- “Top act” in 2012 had been the celebration of the 40th anniversary of Deutsche ILCO in Munich where the first chapter was founded. About 300 participants followed the interesting reports and discussions between ILCO-volunteers, co-operators and wellknown professionals. They highlightend the most important steps of the voluntary work of our association since 1972 and put it into relation to the medical and psychosocial development. It was a great pleasure to welcome the EOA president at this event as well as guests of the national ostomy associations of the Netherlands, Denmark, Luxembourg, Switzerland, Austria, Czech Republic, Poland and Ukraine. Two nice evenings gave time for talking, dancing, speeches and much laughter. The whole anniversary conference ended with a guided city tour.
- In November 2012 the long-term chairman of Deutsche ILCO, Prof. Dr. Gerhard Englert, retired after 37 years. This was a deep cut although the remaining members continued to perform their duties. Nevertheless the work could be continued and developed.
- Since 2005 Deutsche ILCO is no longer only an ostomy association but also the national colon cancer selfhelp association. This affords a lot of additional efforts to build up a structure to fulfill the requests of people with colon cancer with or without an ostomy. Information and materials must be developed. Volunteers need information about the problems of people without an ostomy or with the special problems after the relocation of an ostomy – and they need advice how to talk to those who don't struggle with an ostomy but with the fact of having colon cancer.
- Cooperation with about 200 Colorectal Cancer Centers: Cooperation is fixed by a written agreement and signed by both, centers and Deutsche ILCO. The agreement fixes defines offers of Deutsche to the patients with colon cancer and/or with an ostomy as well as the support of these offers by the hospital/center. Deutsche ILCO offers f.e. visiting service, information about the Deutsche ILCO and the life with an ostomy/with colorectal cancer, cooperation in congresses of the centers. Every volunteer bind himself to strict data protection.
- A big success had been the participation in the development of the National Guideline for the treatment of colorectal cancer (S3-Leitlinie KRK): For the first time it is fixed in a German treatment guideline that the best positions of a possible ostomy must be marked before the operation (in sitting, staying and laying position of the patient). We are convinced that the number of bad positioned ostomies which are the reasons for many ostomy care problems of too much ostomates will decrease – and not only for ostomates with colon cancer but also for ostomates with inflammatory bowel diseases or other causes.

Brochures available:

- Colostomy / Ileostomy – a guideline
- Urostomy – a guideline
- Irrigation – a method for colostomates to clean the colon
- Nutrition after ostomy and colon surgeries
- Lust for live – experiences of ostomates
- Colon cancer – living with the impacts
- Ostomy Dictionary: 103 ostomy terms in 15 languages
- Check out! – A glossery of medical terms

... and other leaflets and advice sheets

Main tasks and challenges from 2014 to 2017:

- The election of a new national board in July 2014
- The integration of people with colon cancer without an ostomy in our association
- To oppose all tempts to worsen the good situation for ostomates (no. of appliances, costs)
- The relaunch of the website
- To stop the trend towards the decrease in the number of members, attracting of new members
- To gain more financial independence which means: To recover more independence of the current grant donors – and at the same time to remain independent of funding by enterprises like pharmaceutical industry or appliance companies